
An Efficient Way to Do the Wrong Thing

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Britain's national health system (NHS) has been embattled since Thatcherism undertook to privatize it. This Britannic version of the new medicine is a hybrid of a neglected, underfunded shadow of the NHS and robust free-market capitalism. The NHS that the Tory government administers is aptly described as topless, bulging in the middle, and suffering chronic battle fatigue at the bottom. The quality of leadership in the NHS has plummeted at the same time thousands of middle managers have been added to prod the frontline caregivers.

The Britannic New Medicine has thrown the medical profession into a *deep re-think of its very purpose*. Recently, the head of a major hospital trust announced: "A physician's first loyalty is to the hospital trust, then to his profession and then to his patients." The outcry from physicians was strong, but clearly the embattled profession is nearing exhaustion. "Everywhere big, ugly buyers are assuming greater power, consumers are more sophisticated, new technology is revolutionising practice, and old ethical issues are being broached in awkward new ways."¹⁻⁴ The engine of change that is afoot is found throughout society—it faces lawyers, accountants, civil servants, university faculty, and now quite acutely, doctors. In business the new arena is global and the conditions for survival are unclear and ever-changing requiring continuous retooling, redundancies, and retraining. In health care a major feature of this new era is that these sea-changes are taking place in a world where resources for medicine are limited.

Problems of resource allocation within medicine arise at a number of different levels. How much of a society's resources should be devoted to health care at all, as opposed to housing or defense? Given some overall allocation of resources to health care, how should these resources be distributed among various different sorts of health care expenditure: For example, primary versus hospital care, or preventive medicine versus care of the already ill. Within such broader categories, how should different specializations be allocated: For example, in the case of hospital medicine between cardiac and obstetric units. And both within and across specializations, what should be the relative allocation for different specific forms of treatment: Kidney transplants versus renal dialysis or hip replacements versus by-pass surgery. Questions of this sort are lumped together as problems of macroallocation. When faced with the relevance of the cost of care, the morally squeamish invoke the *macro/micro* distinction, asserting that economic considerations are morally relevant only to macro allocation decisions and that cost has no relevance in the micro medical/moral decisions of clinical practice.

Health Economists' Proposal of QALYs

Health economists have devised a vehicle for resource allocation—the Quality Adjusted Life Year or QALY. The QALY analysis in the eyes of NHS managers is now on even terms with

the status quo decision making which has been characterized as MSW (management by shroud waving). In the words of Mooney: "MSW where individual clinicians press for more resources for their patients by 'announcing publicly that unless resources are increased patients will suffer and die unnecessarily.' Each individual clinician has, after-all, spent his professional life assessing his patients' distress and disability and the risk to their lives posed by disease."⁵ MSW calls on the physician's abilities as ravers rather than reasoners, and thereby leaves them searching for a better method for allocation decisions.

Economists with an interest in health care introduced the concept of QALY in the 1980s as the key to rational resolution of resource allocation decisions in a time of scarcity. Initially, such economists offered QALYs as a cure for the haphazard or otherwise ethically inappropriate allocation of scarce medical resources without distinguishing between macro and micro allocation decisions. Currently, most major advocates see QALYs as a macro allocation tool while others would apply it throughout health care including case-by-case decisions in clinical practice.⁶⁻¹⁰

The health economist argues that we should prioritize interventions in terms of the quantity of well life measured in quality adjusted life years (QALYs) produced by the intervention per unit of cost. This implies that an intervention that takes N people from a bad condition (including dying) to the state of healthy for X years should have priority over an intervention that takes N other people from the same bad condition to a state of moderate illness for the same number of years. This sort of analysis gives confidence to resource managers, and those who have a consequentialist view of morals. There does seem to be something right about an attempt to rationalize the allocation of scarce medical resources, to examine our priorities in light of argument and evidence of their relative efficacy. The health economist view as represented by Alan Williams appears positively benign: "The objective of economic appraisal is to ensure that as much benefit as possible is obtained from the resources devoted to health care."¹¹

Elaboration of QALYs

A natural response to allocation problems is to say: One should put one's resources where they will do the most good. Perhaps one should, but what does one mean by "the most good"? One kind of good that health care can achieve is saving lives. So one measure, albeit a very crude one, of the good that health care does would be the overall extension of life expectancy that it generates: Years of life gained. This is where QALYs come in. An extended passage from Britain's major advocate of QALYs is in order.

"The essence of a QALY is that it takes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life

expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the 'quality adjusted' bit is all about). If being dead is worth zero, it is in principle, possible for a QALY to be negative, ie, for the quality of someone's life to be judged as worse than being dead.

The general idea is that a beneficial health care activity is one that generates a positive amount of QALYs, and an efficient health care activity is one where the cost per QALY is as low as it can be. A high priority health care activity is one where cost-per-QALY is as low as it can be. A high priority health care activity is one where cost-per-QALY is low, and a low priority activity is one where cost-per-QALY is high. Thus an activity that generates only two QALYs but costs only £200 (so that each QALY costs £100 to produce) is more efficient than one that generates 5 QALYs but costs £2,000 (so that each QALY costs £400 to produce).¹²

What is new or special about QALYs? The QALY is a measure which: First, combines a) life expectancy, b) quality of life, and c) reflects the values of the community served; second, it is welfarist, ie, designed to promote the greatest welfare (health) of the community served; third, it incorporates democratic and equalitarian features; and fourth, it is a rational/objective decision procedure—as scientific as one can get in the social sciences.

There are four assumptions that are required for a QALY analysis: 1) objective of health care system is to improve health, 2) the general public is competent to express its preferences on health, 3) it is possible to elicit meaningful valuation statements from people about differing degrees of health, and 4) it is possible to aggregate these valuations.

How are QALYs constructed or computed? Williams points to research that shows there are numerous ways for health economists to do this, one of which is called the Rosser illness states index. The initial phase of obtaining the "quality adjustment" involves Rosser's system of describing eight states of health¹³ and four degrees of distress (none, mild, moderate, and severe). These illness states are meant to be very general so that they could cover a wide range of actual experiences of ill-health. Matched with the four distress levels the illness states generate 32 possible *disability-distress states*.

Rosser obtains the values (Table 1) by asking participants to rank 29 states (three lack meaning) in order from best to worst. State I-A (No disability, no distress) is clearly the best, but views vary considerably about the worst state. Respondents are to assign "1" to the healthy state, "0" for death, and a negative value for worse than death. Thus one might assign a .5 to state VI-C, with the implication that two years of life expectancy in that condition is of equal value to one year of healthy life expectancy. The values found on the table provide the matrix derived from 70 respondents. The concept of QALYs does not depend on acceptance of Rosser's index, many others have been devised by busy social scientists. At this point we need only grasp what these health care economists are up to.

Once we get this far it is a matter of arithmetic. We take what we know about the costs of procedures, probability of outcomes of treatments/procedures, and with the Rosser index, we are able to compute the QALY and the comparative efficiency of our medical efforts. A hypothetical example from Williams and his formula: "A treatment may offer a 0.8 probability of 10 QALYs, a 0.1 probability of none, and a 0.1 probability of -5 QALYs (ie, the loss of the equivalent of five years of healthy life

Table 1.—Rosser's Valuation Matrix: 70 Respondents

DISABILITY RATING	DISTRESS RATING			
	A	B	C	D
I	1.000	0.995	0.990	0.967
II	0.990	0.986	0.973	0.932
III	0.980	0.972	0.956	0.912
IV	0.964	0.956	0.942	0.870
V	0.946	0.935	0.900	0.700
VI	0.875	0.845	0.680	0.000
VII	0.677	0.564	0.000	-1.486
VIII	-1.028	N/A	N/A	N/A

Fixed points: Healthy = 1, Dead = 0

expectancy)...we could say that the 'expected' value of the benefits from treatment is $(0.8 \times 10) + (0.1 \times 0) + (0.1 \times -5)$ which is $8 + 0 - 0.5$ or 7.5 QALYs."¹⁴ Given adequate information health economists can generate tables that report the "cost per QALY" of practices and procedures from family practitioner's advice to stop smoking to hospital dialysis (Table 2).

Advocates of the QALY approach are quick to point out that they are not offering a precise answer to the question, how many QALYs a given period of life adds up to. Rather they are offering a rational approach to determine how resources should be allocated. Not only does their method reveal that some treatments are more cost-effective than others, but it produces the same outcome even if we experiment with the assignment of values we put in the equation. This is part of what Williams

Table 2.—Cost per QALY Estimates for North America 1983 Data

Procedure	Cost per QALY
Coronary artery bypass grafting (CABG) for left main coronary artery disease	4,200
Neonatal intensive care (1000 to 1499 gm)	4,500
T4 (thyroid screening)	6,300
Treatment for severe hypertension in men aged 40 plus (diastolic 105 mm Hg)	19,100
Treatment for mild hypertension (94 to 105 mm Hg)	19,100
Estrogen therapy for post-menopausal symptoms in women without prior hysterectomy	27,000
Neonatal intensive care (500 to 999 gm)	31,800
CABG for single vessel disease, moderately severe	36,000
School tuberculin testing program	43,700
Continuous ambulatory peritoneal dialysis	47,100
Hospital dialysis	54,000

Table distributed at a BMA conference, 1986, Oxford, England

meant earlier when he says that the QALY analysis does not depend on the Rosser index, other indexes result only in differences in degree and leave in tact the rankings of treatments as found on Table 2. Given the situation of limited resources and more than enough beneficial procedures to exhaust resources, some beneficial procedures cannot be undertaken. QALYs provide us with an objective guide to make the needed choices.

It is difficult to sustain a convincing skepticism about a proposal that offers a method that reveals a way to select among treatments/procedures which will confer greater aggregate benefit than less. It is for this reason that the QALY analysis is being taken seriously in decisions regarding allocation. But this is not

to say that QALY considerations should be regarded as decisive. QALYs need to be measured against considerations of just distribution of the harms and benefits.

Supposing that we are clear about what it is that we are trying to measure, there would still be room for considerable skepticism about the extent to which it was possible to measure it. The idea of putting a yardstick up against a life and reading off some numerical value representing its quality is worrisome, if not preposterous. Philosophers have long debunked the efforts of those who have attempted to divine ways to compare the value of one year of life under circumstances A with those of circumstance B *even* if it were the same life. It is clear that the QALY analysis involves troublesome interpersonal comparisons and asserts that it is a common measure in which everyone's claims of happiness are in some sense comparable and additive. This is a classical problem for utilitarian efforts to compare "utilities" and the health care economists seem to be up to much the same business. Many of the numerous objections to classical utilitarianism have a bearing on the plausibility of the efforts of the health economists. The ongoing discussion about utilitarian theory is robust, indicating that many issues are still quite unresolved.¹⁵

Doubts about QALYs

Economists say that in allocation decisions the key question is a matter of efficiency, more health for the same money. The health economists seem to be engaged in a bit of covert imperialism by eclipsing the ethical dimension of the question for which there is no scientific (economic) answer. Furthermore, the apparent objectivity of the economic approach is very seductive to those who have budget targets to meet and thereby is extremely dangerous.

The problem of ranking values is an ancient one and a great deal of human genius has been expended an effort to quantify value. The ancestry of the modern efforts is easily traced to the British utilitarian philosophers and social reformers, most famously, Jeremy Bentham.¹⁶ There is rich literature detailing the unsatisfactory efforts to develop a *felicific calculus*.

Who's pleasure (happiness) is to count? Well anybody's and everybody's. The objective of government is to create a harmony of interests such that the happiness of as many people as possible is promoted. Where arianism goes wrong is that it is promoting happiness in the abstract rather than the happiness of persons (it separates the individuals from the happiness by abstracting the happiness). Utilitarianism is the combination of welfarism, sum-ranking, and consequentialism. Such a theory separates value from valuers and merges the utility bits together as one total lump. Welfare economics and preference theory are efforts to overcome these difficulties.

Some concerns that shed serious doubts on the moral status of this method of resource allocation: The concerns can be arranged as 1) questions about valuing, 2) the distinction between descriptive and normative ethics and the relevance of democracy to morals, 3) questions about justice, and discrimination against the elderly and the disadvantaged.

Questions about Valuing

Recently there have been numerous efforts to determine what we value in health care and how we would rank services and interventions. The community consensus-building method used in Oregon to rank health care interventions is one effort. Social scientists have conducted numerous studies to establish health

indexes. A study conducted in New York of health graduates and health professionals had results that should raise doubts about objective, democratic efforts to determine preferences.¹⁷ The subjects were asked to assign numerical values to saving lives of people in different states of illness in relation to saving lives of healthy people. The priority was clearly for the healthy. For instance, saving the life of a healthy person was considered approximately equivalent to saving the lives of two people with visual impairment, and three people sitting in wheelchair and unable to work.

Recent studies in Norway suggest that Norwegians reject the primary value of health economists, efficiency, in favor of life itself.¹⁸ Thus, efforts to prioritize on the basis of gained life years is rejected as incommensurable with gained lives. The vast majority in this study held the view that individuals are equally valuable and equally entitled to treatment irrespective of differences in their health or levels of disability.

The health economists are quick to point out that the QALY approach is not dependent on any particular index. But from the two examples mentioned a very pressing question comes to mind: What is it that we have when we have the QALYs based on any index? What is the moral basis or foundation for this standard? Whether we use the Rosser, New York, Norwegian, Oregon, or other indexes¹⁹ what we have is a standard based on a quantification of the values of those in the study. Nothing more.

If we are a mean society we will do X, if we are sympathetic, we will do Y. Such an analysis does not tell what we ought to do, nor does it tell that X or Y is morally defensible. Niggardly and liberal societies will produce different QALYs.

Another concern that must be mentioned has to do with our ability to measure "quality of life" in any meaningful way. Part of the skepticism about any index that the health economists will use is based on doubts about measuring "quality." There are serious unresolved problems about quality measurements, especially interpersonal comparisons and evaluations. These indexes at best tell us about the people who participate. If you change the life experience of the index-making group, you could get very different results. The views of cancer patients, quadriplegics, New Yorkers, Norwegians, Oregonians, etc., on the quality and value of their respective lives are very interesting but certainly incommensurable. And surely there is something utterly preposterous and morally outrageous about the health managers who take seriously the New Yorkers' view that my life is worth the life of three wheelchair-bound people. Something has gone wrong with the new math of health economics that it could support such a view. Yet the QALY math of the advocates of the new medicine implies this as well as other moral outrages.

Descriptive and Normative Ethics

Two points need to be made at this juncture. First, the outcome of such studies are merely a reflection of the different study groups. Surely the inheritances of the past and the differences in cultural conditioning affect the preferences of the subjects. The Norwegian adherence to the principle of equal entitlement to treatment has long been reflected in their national health service with very limited out-of-pocket payment. Thus they do not make good subjects for QALY index studies. On the other hand it is not surprising that in the American studies economic considerations are emphasized in these indexes of values. Bernard Williams points out: "Utilitarianism is not surprisingly the value system for a society in which economic values are supreme; and also, at

the theoretical level, because quantification in money is the only obvious form of what utilitarianism insists upon, the commensurability of value."²⁰ The differences between the New York and the Norwegian study does not surprise and raises serious doubts about the "objective quality" of the QALY standard for allocation decisions.

The echo of utilitarian ethics runs strong through the QALY approach. In its narrowest form utilitarianism seeks the greatest happiness of the greatest number when happiness means pleasure and absence of pain. The health economists seek to eliminate inefficiency (reduce pain at the lowest cost) through discovery of a common measure, QALYs. But a central element of the common measure that they have devised is an uncritical account of the attitudes and values of the subjects of the index generating studies.

Second, ethicists are not given to doing ethics by opinion poll or the results of social scientists' descriptive studies. Allocation decisions based on QALYs utilize a democratic approach of determining the values of society and conclude that such an allocation is morally right. Such a conclusion does not follow. Even if their index was sufficiently representative and free from value loading by the evaluators that does not justify the move from an account of what their sample believes about states of life to how resources ought to be allocated. If their index is of how matters ought to be, the question remains what makes democratic majorities morally right? If on the other hand the index does not purport to tell us "how matters ought to be," then the health economists are not addressing our ethical problem. They are not answering the question: What would be a morally defensible allocation? Rather they are telling us here is an objective method of determining what collectively we would do. Mind you, not what we *ought* to do, just what we would do to most efficiently use our resources.

Reformers and advocates for the disadvantaged in society know better than appeal to what is commonly done or thought. The status quo is what they are trying to change. Rather they appeal to moral or legal arguments in order to obtain equal or sensitive treatment. Descriptive morality does not answer the normative question.

Questions about Justice

Allocation according to QALYs seem unjust in that it would favor those who are more healthy or fortunate. Unlike the classical utilitarianism of Bentham where "everybody to count for one, nobody to count for less than one," the health economists by counting QALYs will allocate to the fortunate, healthy, or young over their unfortunate, unhealthy, or elderly counterparts. Consider two candidates for a treatment where the only difference is that one is suffering from a condition (say, emphysema) unrelated to the immediate problem and the other is not. Assume that the quality of life of the emphysema patient is significantly impaired but there is no reason to suppose it will in any way affect the chances of the treatment under consideration proving successful. Assume also that both patients have an equally intense wish to go on living. Under the QALY assignment of resources the treatment goes to the person without the emphysema. It is a straightforward matter of arithmetic and probabilities. The QALY value for the treatment goes up for every year the one person is likely to live over the other. Clearly this system favors the fortunate and visits further misfortunes on the unfortunate by denying benefits in allocation decisions.

A parallel account works for age or any disability that shortens

a person's life. Replace "emphysema" with "age/older" and you get the same result. Other things being equal, more QALYs are generated by expenditures on the young than the old and on the healthy than on the disabled. QALYs favor the young and the more healthy in any given selection.

A central value of health care has always been to assist those most unfortunate. Paying attention to the unfortunate, those whom nature has dealt a poor hand, has long been a measure of the moral quality of a society. Theories of social justice, certainly since Rawls,²¹ have had to be sensitive to a principle that requires that those least well off must be benefited if anyone else in society is to benefit. The health economists' QALY allocation scheme is not only utterly blind to this principle of justice, QALYs fail to require that the worst-off groups' level of well-being is raised whenever another groups' is to be raised. In fact they allocate in a manner that often increases the disadvantages of those with whom nature has dealt harshly. Rejecting QALYs as an allocation tool Harris enjoins: "What we should not do is abandon those whose quality is poor to concentrate on the fortunate. QALYs require us to do precisely this."²²

Williams has denied that QALYs are ageist by pointing out that they support the funding of hip replacements, an intervention overwhelmingly for the elderly. This denial is unconvincing because the ageism remains within the group in need of hip replacements, other things being equal, the QALY approach would select the youngest candidates. There is a sense that QALYs themselves are not ageist or sexist or anything but blind, and their outcome takes us back to decisions insensitive to our sympathies for our fellow humans. Whereas Rawls' theory of justice has firmly advanced the difference principle, (if we are to treat people differently, then the least well off must benefit from such treatment), the QALY accounts have retreated even from Bentham's equalitarian concept of justice. As Brock has pointed out in discussing quality adjustments for significant group differences: "...a lower quality is assigned to life years for the elderly, or for seriously disabled or handicapped groups, than to life years for normal adults."²³

This explanation of the QALY approach and analysis challenges the ethical suitability of QALYs, in both macro and micro health care allocation decisions. This discussion suggests that whatever the mechanism of allocation it must pass the constraints imposed by ethical considerations of social justice. Furthermore, we have come to see that in QALYs health economists have found an efficient way to do the wrong thing.

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Some Ethical Principles for Adult Critical Care

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State of the art in approaching several of the most disturbing problems involving end-of-life decision-making in an intensive care setting is applicable to other contexts as well. Developed as part of the curriculum at the John A. Burns School of Medicine at the University of Hawaii, the material is intended as a reflection of current work in health care ethics, strongly supported by literature, and generally consistent with current legal trends. But it also has developed into something of a consensus document, having been widely circulated in various versions, repeatedly presented to professional audiences dozens of times in Hawaii, and improved by countless comments and suggestions. The focus here is on the standards for withholding and withdrawing treatment. It should be noted that some important types of ethical problems are not covered: In particular, scarce resource problems (including some related questions involving medical futility), maternal-fetal and pediatric issues, and questions involving the notification of potentially affected third parties.

Decisionally Capacitated Patients

For decisionally capacitated patients, it can be axiomatic that health care professionals must secure informed consent prior to treatment. There is almost no debate about this issue. The little discussion is occurring only at the distant margins—refusals by pregnant women and patients with MDR TB. And even in these cases it cannot be said there is a consensus that contradicts the axiom. In essence, where informed consent has been withheld or withdrawn, health care professionals, lacking needed permission, are not at liberty to treat. Refusals of treatment by

decisionally capacitated, informed adults are decisive: Relatives and health care professionals have no ethical or legal authority to overturn their medical decisions.

Competency and Decisional Capacity

All adults are presumed to be competent and decisionally capacitated. This assumption is rebuttable. In this context, the term “incompetency” must be distinguished from “decisional incapacitation,” by far the more useful of the two concepts. The former is a legal status that is imposed by courts. A judge, generally following the testimony of a psychiatrist, can find an adult to be legally incompetent and will therefore appoint a guardian who is empowered to make decisions on behalf of the adult, now a ward. Judicial declarations of incompetency are rarely required in the ICU. On the other hand, capacity and incapacity are action-specific concepts that are often clinically applicable. As regards some health-care decision, a patient is sufficiently capacitated to make that particular decision if, at a minimum, he or she has the capacities 1) to understand the problem, 2) to understand the risks and benefits of the available alternatives (including no treatment), and 3) to express a choice. It is possible for a legally incompetent patient—for example, a mature minor—to be decisionally capacitated. Likewise, a competent patient may be decisionally incapacitated, as when a patient is in denial about the medical problem.

Informed Consent

Consistent with this analysis of decisional capacity as a minimum standard, a patient is sufficiently informed to give informed consent if he or she:

1. Understands the medical problem,
2. understands what the health care professional proposes to do,
3. understands the available alternatives, including no treatment, and

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